

Multiple  
Sclerosis  
Trust



Making  
Sense of MS



## My MS team

### My neurologist

Name \_\_\_\_\_

Contact details \_\_\_\_\_

\_\_\_\_\_

### My MS nurse

Name \_\_\_\_\_

Contact details \_\_\_\_\_

\_\_\_\_\_

### My next appointment is:

With \_\_\_\_\_

On \_\_\_\_\_

Multiple Sclerosis Trust  
Spirella Building, Bridge Road, Letchworth Garden City,  
Hertfordshire SG6 4ET  
T. [01462 476700](tel:01462476700) T. [0800 032 3839](tel:08000323839)  
E. [info@mstrust.org.uk](mailto:info@mstrust.org.uk)  
[www.mstrust.org.uk/makingsenseofms](http://www.mstrust.org.uk/makingsenseofms)

Registered charity no. 1088353

## **How will this booklet help?**

This booklet is for people who have recently been diagnosed with MS (multiple sclerosis). It has been prepared by the MS Trust, a national charity which supports people with MS.

Being diagnosed with MS may have been a complete surprise or it may have been the largely expected end to a very long journey. You may feel emotional and probably have lots of questions.

## **The MS Trust can help you.**

We can give you as much information as you'd like, either now or later.

Every week our Information Team speaks to people who are newly diagnosed and all our resources are developed in partnership with people who have MS – people who have been in the same place as you.

You can send for more information using the order form on the fold out back page.

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## **What is MS?**

**MS stands for multiple sclerosis which is a lifelong condition that affects the central nervous system (the brain and spinal cord).**

MS affects different people in different ways. In any one person, the symptoms can vary from day to day. It is not fatal and most people with MS live about as long as everyone else.

There is a wide range of possible symptoms. Some of the most common for people who are newly diagnosed are fatigue (a kind of exhaustion), stumbling more than before, unusual feelings in the skin (such as pins and needles or numbness), slowed thinking, or problems with eyesight.

Not everyone experiences all of them.

*Like to know more? Choose:*

***About MS***

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## How do people respond to diagnosis?

Everyone is different.

Whatever you feel, it's OK.

At first, people can feel shocked and unable to take in what has happened. It may even feel as if it is happening to someone else and you are watching yourself from the outside.

Some people feel very emotional – including being angry, worried, fed up or tearful.

Some people feel relieved – at last they have an answer after years of trying to find out the reason for their symptoms.

Some people experience a lack of emotion which is OK too – being diagnosed with MS is a lot to take in.

Many people's feelings go up and down and coping with this can be a learning process.

*Like to know more? Choose:*

***MS and your feelings***

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## **What about my family and friends? Who to tell, when to tell them, and what to say are common questions.**

Your diagnosis will probably affect those around you. They will have their own questions about MS and what it means for all of you. They will have their own way of dealing with your diagnosis which may surprise you and be different from your own.

### **It is good to talk!**

It may be tempting to keep quiet but being open about your diagnosis, and how you are feeling, can be really helpful.

You might prefer to tell those closest to you first. You may need some time to learn about MS yourself, before explaining it to many others. We have information you can give to people that may help them to understand your MS.

*Like to know more? Choose:*

*Telling people*

*A short guide to understanding my MS (to give to other people)*

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## Is there anybody I have to tell?

You must tell the DVLA if you hold a driving licence. They may contact your doctor or ask for an assessment. They may review your licence every few years.

You may also need to contact companies that have issued your insurance. Take a look at the small print to see if you need to tell them straight away. If in doubt, give them a call.

You may like to think about when would be the best time to tell your employer. In some jobs, it is a requirement so you should check your contract.

You might want to tell your manager or close colleagues especially if you need time off for appointments or adjustments made at work. Also, symptoms can appear invisible to others or their cause may be misunderstood.

*Like to know more? Choose:*

[\*Telling people\*](#)

[\*Working and studying with MS\*](#)

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## Why did I get it?

People often wonder:

Did I do something wrong?

Could I have stopped MS from happening?

The answer to these questions is **no!**

The causes of MS are not well understood but it seems that a number of different factors add up to trigger the condition. Some of these factors are in the world around us (possibly including lack of sunshine and vitamin D).

Did I get it from my parents?

Will I pass it to my kids?

MS is not inherited like some other conditions and most people have no previous family history of MS. Some genes make it more likely that someone gets MS but having these genes is definitely not enough on its own.

*Like to know more? Choose:*

***About MS***

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## **Are there different types of MS?**

There are three main types:

Relapsing remitting MS (RRMS)

Primary progressive MS (PPMS)

Secondary progressive MS (SPMS)

The majority of people are diagnosed with relapsing remitting MS but 10-15% of people have primary progressive MS. Only a very small number will be diagnosed with secondary progressive MS.

### **If you don't know your type of MS**

You could make a note to ask your MS nurse or neurologist at your next appointment although they may not know yet.

Deciding the type of MS can take some time but keeping a diary, with brief notes on any new or more troublesome symptoms, can help your MS team work out your type of MS.

*Like to know more? Choose:*

*[Relapsing remitting MS: an introduction](#)*

*[Primary progressive MS: an introduction](#)*

*[Secondary progressive MS: an introduction](#)*

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## Which health professionals will help?

### Your MS team will support you.

Many people are referred to an MS nurse. They specialise in supporting people with MS and are likely to be your regular point of contact. They will discuss your diagnosis and any questions you may have.

You probably saw a neurologist for your diagnosis. Not all neurologists are MS specialist doctors so you may be able to transfer to one now that you have a diagnosis.

You should be referred automatically to these MS services but, if you'd like to find their location, go to our map at [www.mstrust.org.uk/map](http://www.mstrust.org.uk/map)

GPs aren't specialists in MS but they can refer you to specialist services and may be able to help with treatments for some symptoms.

*Like to know more? Choose:*

*What happens after diagnosis?*

*Making the most of appointments*

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## **How much will MS affect my life?**

### **Will it stop me doing what I'd like to do?**

After diagnosis, it may feel like life has changed in a big way or it may seem exactly the same but with the 'MS' tag added.

MS affects everyone differently and it is not possible to predict exactly how a particular person will be affected. Symptoms usually vary from day to day and year to year. Some people experience disability due to MS but this is not the case for everyone.

Many people with MS are diagnosed at a time in their lives when they are making key life choices like whether to settle down, have children and build a career.

Being diagnosed with MS may not change your plans so don't feel pressured into making decisions too soon after diagnosis.

*Like to know more? Choose:*

***MS and life choices***

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## Are there changes I can make?

People often ask what they can do.

MS is a lifelong condition but there is a lot you can do to be as well as possible.

People living with MS often say that the most important thing is to live each day as it comes. Accepting this can be a way to move forward.

Trying to be positive and taking charge of managing your MS, with the support of health professionals, can also be key.

When it comes to lifestyle, the advice for people with MS is the same as for everyone – eat healthily, exercise sensibly, avoid smoking and try not to drink alcohol to excess.

Also, listen to people who know about MS. You may encounter a wide range of opinion but use your judgement and choose wisely. It's your life.

*Like to know more? Choose:*

***Living well with MS***

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## **What about treating symptoms?**

Whatever kind of MS you have, there are treatment options that you can discuss with your MS team.

Treatments include medication, physiotherapy or a change in lifestyle.

You might like to prepare for your next appointment by keeping a brief diary. Recording which symptoms are most troublesome, and when they happen, can help you explore your treatment options.

At present, there is no cure for MS but there are good options to manage the condition.

## **What about research?**

MS is a very active field of research. Research has already made a big difference and further treatments for managing symptoms and reducing relapses are coming through.

*Like to know more? Choose:*

*[Treating symptoms](#)*

*[Research and MS](#)*

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## **What about relapses?**

The symptoms of MS vary from day to day for most people. On top of this, some people experience relapses, which are new or much worse symptoms, lasting anything from one day to a number of weeks. Some relapses are relatively mild but some have a greater effect. Symptoms usually improve and sometimes go away completely.

Relapses may be treated with steroids in the first few days to speed up recovery.

It is not possible to predict when relapses will happen or how often. Every person's MS is different and so is every relapse. This is one reason that MS is often described as unpredictable.

If you have relapses, talk to your neurologist or MS nurse about disease modifying treatments (DMTs). These can decrease the frequency and severity of relapses.

*Like to know more? Choose:*

[\*Disease modifying treatments: an introduction\*](#)

[\*Relapsing remitting MS: an introduction\*](#)

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## Where can I get good information?

### The MS Trust can help.

Getting reliable information is important. It is best to avoid looking for information online using a search engine when you are first diagnosed unless you only click through to the most trusted sites.

### About us

The MS Trust is a UK charity with over 20 years experience of supporting people with multiple sclerosis. We supply free information to anyone affected by MS including friends and family. We rely on donations and fundraising by our supporters.

### Take your time

You might like to begin with the topics that are most important to you. You can gather information at your own pace and only explore in depth if you feel you need to. Some topics may never apply to you.

*Like to know more? Choose:*

***Sources of information and support***

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## Where should I begin?

You could send for our Making Sense of MS information pack.

It contains some core information in a handy folder. You can also choose any of the optional sheets, either now or at any time in the future.

Tick the corresponding boxes on the order form on the fold out back page.

### Or view it online

If you prefer, you can use the order form as a prompt to browse the information on our website.

Our website also has some videos of people talking about being diagnosed with MS. You might also like to join our online communities on Facebook and Twitter.

Go to:

[www.mstrust.org.uk/makingsenseofms](http://www.mstrust.org.uk/makingsenseofms)





## **What if I have a question?**

**No problem, get in touch.**

The MS Trust Information Team is here to help answer your questions about MS. It could be something really general or something very specific.

Give us a call on:

**0800 032 3839** or **01462 476700**.

(Monday – Friday, 9am – 5pm)

Or email us at [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

## **What about in depth information?**

We have a range of other printed publications, as well as more information on our website. You might like to start with the free *Making Sense of MS* information pack and then follow the pointers to the topics that are important to you.

*Like to know more: Choose:*

***Publications for people with MS from the MS Trust***

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## What's in the free information pack?

The Making Sense of MS pack contains information:

About MS

What happens after diagnosis?

Making the most of appointments

Living well with MS

Sources of information and support

Publications for people with MS from the MS Trust

You can choose optional information on:

MS and your feelings

Telling people

A short guide to understanding my MS (to give to others)

Working and studying with MS

Relapsing remitting MS: an introduction

Primary progressive MS: an introduction

Secondary progressive MS: an introduction

MS and life choices

Treating symptoms

Research and MS

Disease modifying treatments: an introduction

You can come back for more information at any time. So can your friends and family.

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### Making Sense of MS

Jane Havercroft

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This edition published 2014

This publication will be reviewed in three years.

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## Please send me an information pack

Name (Mr/Mrs/Ms/Other) \_\_\_\_\_

\_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Postcode \_\_\_\_\_

Telephone number (optional)

\_\_\_\_\_

Email (optional)

\_\_\_\_\_

### Data Protection Act:

MS Trust and our trading company value your support and promise to respect your privacy. The data we gather and hold is managed in accordance with the Data Protection Act (1998). We will not disclose or share personal information supplied by you, with any third party organisations without your consent. We would like to keep you informed about the vital work we do; if you do not want to receive this information please let us know.

\_\_\_\_\_

## Order form

Please tick the boxes for the information you'd like.

- Making Sense of MS pack containing:
- About MS
  - What happens after diagnosis?
  - Making the most of appointments
  - Living well with MS
  - Sources of information and support
  - Publications for people with MS from the MS Trust

Optional information on:

- MS and your feelings
- Telling people
- A short guide to understanding my MS (to give to others)
- Working and studying with MS
- Relapsing remitting MS: an introduction
- Primary progressive MS: an introduction
- Secondary progressive MS: an introduction
- MS and life choices
- Treating symptoms
- Research and MS
- Disease modifying treatments: an introduction

Have you filled out your contact details on the opposite page?

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## What are my options?

You can choose to:

Return the tear off portion to us. Just separate it along the perforation, lick then stick the two halves together and pop it in the post.

Phone in your order on:

0800 032 3839 or 01462 476700

Order online at:

[www.mstrust.org.uk/makingsenseofms](http://www.mstrust.org.uk/makingsenseofms)

Use the tick list as a prompt to browse the information on our website at:

[www.mstrust.org.uk/makingsenseofms](http://www.mstrust.org.uk/makingsenseofms)



Open this fold-out page to reveal the order form.



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